



Summary of the Information day held in Honiton on 3rd June 2009

The day was aimed at providing parents with a variety of information on a range of subjects in answer to many of the questions that have been asked over the past couple of months and to give everyone the opportunity to talk about any concerns.

Topics covered during the day were:

- East Devon Activity Scheme/ holiday schemes
- Direct payments – Sarah Dixon, Direct Payments Co-ordinator, East Devon
- School Transport
- Research into interventions for Children with Additional Needs – Claire Lloyd, Cerebra Research Unit
- What help, support and information parents find useful
- Joint Agency Service updates – Jennie Waldron, Joint Agency Service, East and Mid Devon
- Any other questions

East Devon Activity Scheme

This item had been added to the agenda shortly before the meeting as parents were starting to raise concern over the increased costs they were being asked to meet.

Overall it was felt that the quality of the scheme had improved considerably of the last year, but the concern was that parents would not be able to fund places for their child this summer. As it is a Devon County Council run scheme parents who receive direct payments cannot use them to buy places. It was discussed how parents who use direct payments but who also wish to access the activity scheme can ask to have some of the payments withheld and days at the scheme provided instead.

It was discussed as to whether they could ask Louise Edmonds of the activity scheme why the costs had been raised to such a level. It was felt that the costs probably represented the cost of a place for the day on a full cost recovery basis and if so, there would be no change to the overall cost. However, it was decided to invite Louise to the September meeting so they could feedback on how the scheme had run over the summer and to voice any concerns they may have.

Sarah Dixon (direct payments) explained that it was vital that parents made certain that any need for the activity scheme or other holiday provision was clearly stated in the Care Plan at the time of the review.

The discussion then moved on to what should happen if the family has no key worker. There is still concern that Care Co-ordination is not working as the workers involved do not know either the family or the children. Parents felt strongly that having one worker deal consistently with a family was very important. They can then get to know the family and start to build a relationship of trust.

Several parents who have no designated key worker feel that it is down to them to organise and arrange everything.

They decided to speak to Jennie Waldron after lunch to ask how the plan for designated key workers was progressing.

Other holiday schemes/services

There followed a general information sharing session about what else was available and how parents might access it.

St Thomas Playscheme

This runs in Exeter for one week during the summer holiday and is for children with additional needs under the age of 12.

For more information contact Nicky.

School holiday schemes

Many schools, both state and private, run holiday schemes that are open to children who do not necessarily attend that school.

It was suggested that if parents find a scheme they should contact the organiser to discuss the needs of their child. There is inclusion funding available to schemes where they need additional help to meet the child's needs.

Agency provision

For some families they may be able to use an Agency to provide a care worker or enabler for their child. Sarah Dixon has a list of some agencies available to parents.

Employing direct

The direct payments co-ordinators are able to help guide parents through the process of employing a worker to help with their child. They can also arrange for the CRB check to be done on the prospective employee.

It was suggested by one parent that it can be a good idea to approach the child's school as sometimes the teaching assistants may be looking for additional work over the summer, and the fact that they already know the child is a bonus.

A parent from Exeter recently placed an advert on the university website for 2 enablers for her child. She received several responses to the ad and now has employed 2 students to take her child out for sessions.

Other ideas/information

Ask DISCplus for a list of holiday schemes/clubs in the area.

For children with an Autistic Spectrum Disorder there are trips for the family organised by AUCHID www.auchid.co.uk

Check with Devon Welfare Rights that you are claiming all the benefits that you are entitled to and see if you are eligible for the childcare element of working Families Tax Credit which may help with childcare costs.

Direct Payments

Sarah Dixon, direct payments co-ordinator for East Devon talked about the importance of the care plan review in relation to direct payments. She stressed to parents that they needed to talk to the key worker about what is needed in terms of breaks and clubs. This then needs to be written into the care plan. The first payment will then be told how much money this will equate to.

Direct payments should be flexible and they should be used to meet focussed outcomes.

Sarah stressed that the tracker forms must be completed and that the tracker form, bank statement and the outcomes on the care plan should all match up.

Claire Lloyd – Cerebra Research Unit

Claire, who is from the Peninsula Medical School, spoke of her role which is to look at interventions for children with additional needs. They are currently looking for suggestions as to what should be researched further and as such are asking parents for their ideas.

Two launch dates are coming up and Claire invited any interested parent to come along and find out more. She is also looking for parents who may be interested in participating on their advisory group.

The dates are:

Tuesday 23rd June

10am – 1pm

The Innovation Centre, University of Exeter, Exeter, and

Wednesday 1st July

10.15am – 1.15pm

The Rolle Building, University of Plymouth, Plymouth

Both events are FREE and lunch is provided. For more information or to book a place please contact Claire on 01392 262901 or email Claire.lloyd@pms.ac.uk

One idea that has been suggested is to do with sensory integration and she will be talking further with Jackie Warne of Ellen Tinkham School about this.

School transport

Nicky had asked for this to be discussed as it is an issue that will be discussed at the County forum shortly and she was interested to hear the views of any parent who had dealings with the service.

Overall parents were very unhappy with the response they encountered when they contacted school transport.

Some of the questions they wanted answered were:

- What training do escorts have?
- Do they have to have it?
- Are all escorts employed by DCC?
- Do drivers get advice/training on how to secure wheelchairs?

Parents also felt that a new Code of Conduct should be written for children with additional needs and felt it was ridiculous that children were being asked to sign their agreement when they had no understanding of what it meant.

What sort of help and information do parents find useful?

There followed a brief discussion in which parents were asked to think about what they had found most useful to them in terms of support and information and what they would find most useful in the future. They were also asked what was least helpful.

Nicky explained that Parent Carers' Voice is continually looking at what parents need and this information will help them to plan meetings, information sessions or other things that would help families.

Jennie Waldron, Joint Agency Service

Jennie joined us after lunch to answer any questions that parents might wish to ask.

She was asked about the training for parent keyworkers. One parent had recently attended the session and felt that it was a little lacking in substance. Jennie agreed to look at what was provided and look at whether improvements could be made.

There was then a discussion around what parent keyworking involved and how much the parent would be expected to do. It was explained that the aim was that it was flexible and that parents could do as much or as little as needed. They are not able to do the assessment for Fair Access to Carers Breaks or write the service plan themselves.

Previously there had been sessions for Parent key workers to get together so they could discuss any problems or find out further information. Jennie would look into whether these sessions still run.

Joint Agency Update

The management restructure is now complete and managers have been appointed to cover the county.

The Integrated Assessment Team is now based at Capital Court on the Sowton Trading Estate in Exeter. This will be the new Early Response Team. Referrals will come through this team initially.

If enduring or complex needs are identified the file will go to the new further Response Team which was previously the complex cases team.

The Child and Adolescent Mental Health Service (CAMHS) will become part of the Joint Agency Service.

Keyworkers

Currently there are more children with the JAS than there are available key workers. It is known that parents want a named worker so they are currently looking at providing a designated worker for most children. This will not happen overnight, but they are moving towards this.